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# Effects of Illness Identity and Perceived Controllability on the Health Outcomes of Patients with Type 1 Diabetes

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# Effects of Illness Identity and Perceived Controllability on the Health Outcomes of Patients with Type 1 Diabetes

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# Abstract

## Effects of Illness Identity and Perceived Controllability on the Health Outcomes of Patients with Type 1 Diabetes

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A patient's *illness identity* is the degree to which a patient's diagnosis is integrated into their sense of self. As a frequent point of discussion for providers, physicians often discuss how providers should not call their patients "diabetic patients;" instead, they should use the phrase "patients with type 1 diabetes." The reminder to providers merely points to the prevalence of how an dillness can become a part of a person's identity, with a patient's illness identity impacting a patient's life in a variety of way, both positive and negative. Although research has begun to show the positive and negative effects of illness identity on health outcomes in a variety of conditions, there is a lack of understanding as to why illness identity has the impact on outcomes that it does. Although *attribution theory* as a whole is not often studied explicitly in healthcare settings, *health locus of control* has gained significant attention. Other elements of attribution theory, particularly *controllability*, can be found in recent research on patient *illness representations*, or a patient's common-sense understanding of a health threat. In

this paper, I review the state of the current literature on illness identity, attribution theory, and illness representation with a particular focus on controllability in medical patient populations. I end this review with a proposal for a study of pediatric and adolescent patients with type 1 diabetes that has as its goal investigating a possible mediation model. I hypothesize that the effects of illness identity on health outcomes are mediated by a patient's perception of the controllability of their illness. In my conclusion, I discuss possible applications and further investigations of this mediation model both within and outside of pediatric and adolescent patients with type 1 diabetes.

*Keywords*: illness identity, illness representation, attribution theory, causal attributions, controllability, type 1 diabetes, pediatrics

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# Chapter 1: Introduction

A patient's identity and beliefs regarding their illness have become important to clinical researchers. The more indicators to which clinicians and healthcare systems can turn to in order to predict patient outcomes, the better they can develop effective and efficient interventions to help patients. As healthcare providers seek to understand the countless variables that influence a given patient's health outcomes, they have begun to look at more than a patient's external environment to predict the course of their illness. Going beyond environmental factors to understand the psychological aspects of having a medical diagnosis provides a more complete understanding of a patient's health and may suggest opportunities for intervention.

An individual's identity is the collection of personal and social attributes that distinguishes the person and links them to others (Masters et al., 2016). This definition is quite broad, so researchers interested in medical patients have developed terminology to focus on how a medical diagnosis specifically impacts the relevant components of a patient's identity. As a result, the concept of *illness identity* has become prevalent. A patient's *illness identity* refers to the degree to which a patient's diagnosis is integrated into their sense of self. Recently, a group of Belgian researchers synthesized a number of conceptualizations of illness identity into one cohesive theory (Oris et al., 2016). Their theory splits up illness identity into the subcategories of *rejection*, *engulfment*, *acceptance*, and *enrichment* in order to characterize illness identity more closely. Additionally, questionnaires have been developed to provide scores for each of these

subcategories. As a whole, illness identity and its subcategories have been studied in the context of a number of different illnesses, and its impact on health outcomes varies based on how a patient identifies with their illness, the type of illness, and even specific diagnoses (Adams et al., 1997; Cruwys & Gunaseelan, 2016; Luyckx et al., 2018; Oris et al., 2016; Reeve & Lincoln, 2002; Rich, 2006; Tilden et al., 2005; Van Bulck et al., 2018). However, nearly all of these studies simply examine the correlation between a patient's illness identity and their health outcomes. There is a lack of understanding of what is mediating the impact that a patient's illness identity has on those outcomes.

With this review and proposed study, I am interested in investigating the role played by a patient's causal attributions regarding their illnesses as potential mediators of the effects of illness identity. *Attribution theory* was first formulated by Fritz Heider (1958) and solidified into its widely accepted conception by the writings of Bernard Weiner (1985). *Attribution theory* aims to investigate how individuals answer "why" questions concerning aspects of their lives (Graham & Taylor, 2016). Regarding patients and their illnesses, causal attributions are considered a crucial component of how a patient perceives their illness (Shiloh et al., 2002). Within healthcare, health locus of control on its own has garnered the most attention (Cheng et al., 2016). When attribution theory has been applied as a whole, the focus has often been on the attributions that healthcare providers have towards patients and treatment efficacy (Dar-Nimrod & Heine, 2010; Phelan, 2005; Stenmar & Nordholm, 1994). When patient attributions have been considered, research has often focused on the psychological impact of diagnoses (Holman & Gregory, 1991; Roesch & Weiner, 2001).

However, another topic of research with medical patients overlaps with investigations of illness identity and causal attributions -- *illness representation*. One of the five elements of the most commonly accepted illness representation model, the Common-Sense Model (CSM) of Self-Regulation created by Howard Leventhal, is the patient's perception of their illness's *controllability* (Leventhal et al., 1998). This concept directly matches the concept of controllability within Weiner's attribution theory. Studies investigating the controllability of illness based on the CSM have shown improved markers of both mental and physical health for patients with many different conditions who report a stronger sense of the controllability of their illness (Alsen et al., 2010; Dickens et al., 2008; Lerdal et al., 2019; Leventhal et al., 1998; Lindberg et al., 2016; MacInnes, 2003; Magklara & Morrison, 2016; Nahlen Bose et al., 2016; Pinto et al., 2013; Pinto et al., 2017; Stafford et al., 2009). However, the vast majority of these studies have been in adult populations, and they lack the nuance provided by the Oris et al. (2016) conceptualization of illness identity. As a result, there is a gap in not only understanding the relationship between the CSM and illness identity, but also in whether or not these conceptualizations hold for pediatric populations and diseases.

Compared to adult populations in the United States, chronic conditions in pediatric and adolescent populations are relatively uncommon, with approximately six in ten adults having a chronic condition whereas only one in four children and adolescents is diagnosed with a chronic condition. However, this number is on the rise in the United States (Centers for Disease Control and Prevention's National Center for Chronic Disease Prevention and Health Promotion, 2020; Van Cleave et al., 2010). Five particularly

significant pediatric chronic conditions are asthma, food allergies, epilepsy, hypertension, and type 1 diabetes (T1DM) (Miller et al., 2016). Although asthma, food allergies, and epilepsy have higher prevalences, T1DM is particularly interesting, in part because it universally requires substantial health management to prevent significant long-term health consequences such as damage to kidneys, peripheral nerves, and the retina (Hamman et al., 2014). Given that approximately 1 in 300 U.S. children are diagnosed with T1DM by the age of 18 (Maahs et al., 2011), the condition represents a particularly fruitful population for identity research in pediatric and adolescent populations (Luyckx et al., 2008).

T1DM is an autoimmune condition where a patient's immune system attacks the beta cells of the pancreas, destroying their ability to perform their normal function of providing insulin for the body (Rosen & Ingelfinger, 2019). Cells in the body need insulin in order to take up glucose (a form of sugar) from the blood to break down for energy, which is particularly important because glucose is the primary energy source for the cells of the brain. The exact etiology of the illness is unknown, but T1DM likely occurs when a patient who is genetically predisposed to the condition encounters some environmental trigger (Rogers et al., 2017). In the United States, T1DM is frequently diagnosed in childhood as the incidence, or rate of diagnosis within a population, is highest in the 5-9, 10-14, and 15-19 age groups, and approximately 85% of children with diabetes have T1DM (Rogers et al., 2017; Chiang et al., 2018). Once a patient is diagnosed, they must administer insulin exogenously through a pump or through syringes

for the rest of their lives as there are currently no therapies to restore the normal function of the beta cells of the pancreas (Pihoker et al., 2018).

These qualities of T1DM contrast with type 2 diabetes (T2DM) because T2DM is typically diagnosed in adulthood as, through a number of complicated mechanisms, a patient develops resistance to insulin due to high blood glucose levels over time (Xu et al., 2018). Although genetics certainly play a role in T2DM, diet and lifestyle have a large impact on its development as well. Patients diagnosed with T2DM are able to reverse their diagnosis if they can regain control of their blood sugars through medications, diet, and/or exercise. As a result, whereas T2DM is not a permanent diagnosis, T1DM is a diagnosis guaranteed to stay with the patient for the rest of their lives, making it particularly interesting from the standpoint of illness identity (Chiang et al., 2018).

T1DM is also useful from a health outcome-standpoint because the treatment, symptoms, and manifestations of T1DM are well documented and understood and because of the existence of hemoglobin A1c (HbA1c), a specific blood test useful for all patients with diabetes (Chiang et al., 2018). HbA1c, or glycated hemoglobin, is a form of hemoglobin that has a sugar molecule bound to it. By measuring a patient's HbA1c, a healthcare provider can determine how well a patient has been controlling their diabetes because it provides a proxy measure of the average amount of glucose in the blood over the course of three months. In turn, this provides a measure of the metabolic and oxidative stress this level of glucose is causing as advanced glycation end-products (AGEs) like HbA1c contribute to the vascular injuries that lead to the long-term

complications associated with diabetes (Meerwaldt et al., 2008). In short, the more glucose there is in the blood on average, the higher the HbA1c and the greater probability of long-term complications as elevated HbA1c levels are associated with a wide variety of risks, adverse outcomes, and all-cause mortality in both T1DM and T2DM (Agiostratidou et al., 2017; Andersson et al., 2012; Wang et al., 2019). HbA1c is a percent value and should be below 5.7% in healthy individuals. According to American Diabetes Association guidelines, a HbA1c value below 7.5% is recommended for all pediatric patients with T1DM (American Diabetes Association, 2018). The combination of all of these factors made T1DM a good starting point for answering my question regarding the relationship of illness identity, causal attributions, and health outcomes.

I propose that much of the impact that illness identity has been found to have on health outcomes can be explained by the causal attribution of controllability that I believe comes with a positive illness identity. I hypothesize that the more strongly a patient with type 1 diabetes accepts their illness and feels enriched by it, the more they will feel like their condition is controllable. This sense of controllability will lead to better adherence to treatment regimens and ultimately to better health outcomes for patients with type 1 diabetes.

The aims of the present project are to: (1) examine whether the illness identity (namely high acceptance and enrichment and low engulfment and rejection identity measures) or causal attributions (namely high controllability measures) of a patient with type 1 diabetes predict positive health outcomes (namely lower HbA1c values and lower PAID survey scores) in pediatric populations, (2) examine whether or not there is a

relationship between illness identity and perceived controllability for pediatric patients with type 1 diabetes, and (3) determine whether or not the effects of the illness identity of a pediatric patient with type 1 diabetes on health outcomes are mediated by the perceived controllability of the illness.

In the chapters that follow, I will start by providing background and a summary of the current literature on the topics mentioned above. Chapter 2 will discuss illness identity, the history of the term, the development of the term as described by Oris et al. (2016), and provide an overview of the studies investigating the ideas in various illness and patient populations. Chapter 3 will cover attribution theory, particularly as it pertains to an individual with T1DM, and will examine the literature of attribution theory as it has been applied in medical settings. Chapter 4 will reveal the similarities between attribution theory and the ideas of illness representation and controllability as discussed in Howard Leventhal's (1998) Common-Sense Model of Self-Regulation before examining the research around this model. I will then propose a study to investigate the existence of a mediation model in Chapter 6. Finally, Chapter 6 will discuss implications of the proposed study, limitations to the proposal, and possible future directions.

# Chapter 2: Illness Identity

## Illness Identity and its Components

In order to propose a mediation model between illness identity and illness controllability, I need to first describe the background of and present the current literature on the topics of illness identity, attribution theory, and illness controllability. In this chapter, I will first lay out the origins and the details of illness identity as formulated by Oris et al. (2016). I will then summarize the current state of the literature on illness identity.

The influence of illness on patient identity has been studied for a long time, in a number of different illnesses, and in a number of different ways. The author that is considered to have first formally written about the connection between illness and identity was Talcott Parsons (1951). He considered illness as a form of dysfunction and used the phrase "sick role." Parsons (1951) believed that, when fulfilling this role, patients should be relieved of all social responsibilities and be excused from their actions to enable the restoration of their health and place in society as they follow the advice of medical professionals. This theory has since been criticized for its inapplicability to patients with chronic illnesses that are never "cured" (Crossley, 1998) and its depiction of medical patients as individuals beholden to medical providers and how society views them and their illness (Lawton, 2003; Pierret, 2003). As a result, different frameworks have been adopted to examine the relationship between illness and identity in order to address the shortcomings of Parsons' initial conceptualization.

A framework that has been used for elaborating on the reciprocal relationship between illness and identity is labeling theory, specifically how illness leads to stigma. Labeling theory originated with the work of Émile Durkheim (1897) in which he discussed how labeling individuals as criminals allows society to control their behavior. The type of label that became significant for research concerning illnesses were stigma, or social labels that act to discredit individuals based on physical appearance, character, or other features (Goffman, 1963). With the discreditation brought on by stigma comes many repercussions, such as discrimination, stereotyping, loss of status, and a separation of the stigmatized group from society as a whole (Link & Phelan, 2001). Most research concerning stigma within illnesses has centered around discussions of patients with mental illnesses.

The stigma surrounding mental illness has been researched extensively, and it has been used not only to identify characteristics commonly found with that stigmatized identity, but also to predict the behaviors of patients diagnosed with mental illnesses. Scheff (1966) was the first to write about the fact that society responds negatively to individuals with mental illnesses in general. As a result, individuals diagnosed with mental illnesses can find it difficult to function within society as they had before their diagnosis. The modified labeling theory of mental illness expands on this idea in an attempt to predict outcomes of and behaviors exhibited by patients with mental illnesses (Link, 1987; Link et al., 1989). The stigmatized label of mental illness predicts such negative outcomes as unemployment and future socioeconomic status (Link, 1987), and individuals diagnosed with mental illnesses often keep their treatment history secret and

remove themselves from interactions with others (Link et al., 1991). These behaviors lead to self-fulfilling prophecies regarding the expectation of rejection held by individuals with such diagnoses (Link et al., 1991).

Although the research concerning the stigma of mental illness improves in some ways upon Parson's conceptualization of the sick role by working to predict actual outcomes and behaviors of patients with illnesses instead of simply prescribing actions, it continued to focus on the negative aspects of the interplay between illness and identity. Although all of the writing previously discussed focuses on individuals labelled as mentally ill by others, there are patients who seek out mental health treatment on their own. By so doing, the patient takes the stigma of mental illness onto themselves. Thoits (1985) has argued that these individuals often experience less significant stigma than individuals who are labelled or treated as mentally ill by others. This is significant because another framework, social interactionism, has sought to capture the individual stories and experiences involving illness (Lively & Smith, 2010), giving more nuance to how illness and identity interact with each other, both negative and positive.

The social interactionist approach to illness and identity relies on accounts from patients themselves and acknowledges how fluid a patient's identity and relationship between their illness and identity truly are. George Herbert Mead (1934) originally conceived of social interactionism, claiming that every individual is a constantly evolving conglomeration of relationships and labels they receive through their interactions with others, and society is shaped by the individuals within it. In such a view, patients have the power back to help shape the world around them, and no one label or stigma can fully

define them. The author who pioneered this approach among medical patients was Kathy Charmaz (1983). Entirely through interviews with patients with numerous medical conditions, Charmaz discovered that patients often experience a loss of certain identities, as their illness impacted identities the patient used to have (Charmaz, 1983). For example, if an individual diagnosed with a chronic illness can no longer perform their job as a professional athlete, they have "lost" that identity. At the same time, personal narratives and labels can lead to more positive connotations for medical patients, such as framing one's self as a "survivor" of cancer who "fought" against the illness instead of a "victim" of their diagnosis (Lively & Smith, 2010). With her continued work, Charmaz developed the concept of an illness identity, or the degree to which a patient's diagnosis is integrated into their sense of self (Charmaz, 1995). This framework has allowed researchers to analyze the different ways illness impacts identity, both positive and negative.

One group of Belgian researchers has sought to integrate a number of both positive and negative conceptions of illness identity into one unified framework (Oris et al., 2016; Oris et al., 2018). Their theory is inspired by Charmaz's (1995) approach to illness identity as well as the work of authors approaching illness identity from a labeling theory framework (Schur, 1971). It combines different sub-categories of illness identity found in the literature (Evers et al., 2001; Helgeson et al., 2006; Morea et al., 2008; Tilden et al., 2005). The four dimensions of illness identity put forth by this model are *engulfment*, *rejection*, *acceptance*, and *enrichment* (Oris et al., 2016; Oris et al., 2018).

*Engulfment* describes how much a patient's illness dominates and defines many different aspects of their identity. This term was originally conceived of as "role-engulfment" by Edwin Schur (1971) within the labeling framework, and it was modified to "engulfment" and used to analyze patients diagnosed with schizophrenia (Lally, 1989; McCay & Seeman, 1998). Schur (1971) discussed how a deviant label, like a diagnosis of schizophrenia, can have an "increased salience or primacy" for the individual "relative to other kinds of roles." In other words, if an individual is unable to distance themselves from their diagnosis, the individual's identity becomes engulfed by their identity as an individual with schizophrenia over all else (Morea et al., 2008). These patients face role constriction, losing all other social identities and roles (Estroff, 1989). Initial studies showed that high levels of engulfment of patients with schizophrenia were correlated with the frequency and duration of both hospitalization and experiencing of hallucinations (Lally, 1989).

*Rejection* concerns the extent to which a patient denies that an illness is part of their identity and views the diagnosis as a threat to their identity. This term was first used by researchers interviewing patients with asthma in South Wales who discovered two different patient types when investigating adherence to treatment: accepters and deniers (Adams et al., 1997). The deniers rejected their identity as asthmatics, and this had an impact on subsequent behaviors. It has since been used to study patients with a number of other illnesses, including diabetes, epilepsy, and inflammatory bowel disease (Andonian et al., 2020; Luyckx et al., 2018; Oris et al., 2016; Tilden et al., 2005).

*Acceptance* refers to how extensively a patient acknowledges their illness as part of their identity without overwhelming other elements of their identity. The idea of acceptance was first formalized by Beatrice Wright (1960), as she claimed that acceptance is crucial for an individual's coping with any disability. The idea of acceptance has been expanded upon to create scales to measure an acceptance score for individuals with disabilities (Evers et al., 2001; Linkowski, 1971). Researchers have used these scale and other approaches to examine the impact of acceptance on many conditions, including epilepsy rheumatoid arthritis, multiple sclerosis, and chronic pain (Evers et al., 2001; McCracken, 1998; Rosenbaum & Palmon, 1984).

Finally, *enrichment* involves a patient believing that their illness has actually enhanced their sense of self and empowered personal growth (Luyckx et al., 2018). Enrichment was inspired by the concept of posttraumatic growth developed by Richard Tedeschi and Lawrence Calhoun (1995). Posttraumatic growth is characterized by the positive change that arises due to challenging life circumstances and the struggles that come with those circumstances (Tedeschi & Calhoun, 2004). Posttraumatic growth and the related concepts of benefit finding and stress-related growth have been found to have beneficial effects on mental health, self-esteem, interpersonal relationships and social supports, and sense of personal strength for both adults and adolescents (Helgeson et al., 2006; Meyerson et al., 2011; Senol-Durak, 2014; Tedeschi & Calhoun, 2004). Oris et al. (2018) took these conceptions and created their idea of enrichment, which focuses entirely on the positive changes that occur in relation to a patient's identity as a result of

their illness. Each of these elements of illness identity have been studied in many settings and have been associated with a variety of outcomes.

## Illness Identity Literature

Using these four categories of illness identity, Oris et al. (2016) developed the Illness Identity Questionnaire (IIQ). They initially developed the IIQ specifically for patients with T1DM, but it has since been applied to a number of different patient populations. As the framework is relatively new, I summarize the literature that has used the IIQ has been provided below, as well as reviewing additional studies that support ideas very similar to engulfment, rejection, acceptance, and enrichment scores.

Patients who score highly in the engulfment dimension of illness identity have generally seen to poor health outcomes. Engulfment has been found to be a predictor of increased healthcare usage (specifically hospitalization rates, specialist visits, and general practitioner visits) as well as higher levels of emotional distress in patients with congenital heart disease (Andonian et al., 2020; Van Bulck et al., 2018). In patients diagnosed with depression, a higher degree of identity centrality (very similar to the concept of engulfment) was associated with greater perception of discrimination and lower general wellbeing (Cruwys & Gunaseelan, 2016). In studies of patients diagnosed with epilepsy, higher engulfment scores and lower acceptance scores were associated with more seizures and medication side effects, and engulfment scores were strongly negatively correlated with patient quality of life (Luyckx et al., 2018). Lower quality of life and higher levels of self-reported fatigue, depression, anxiety, and symptoms of the

illness were found to be correlated with high engulfment scores in patients diagnosed with inflammatory bowel disease (Knödler et al., 2020). High levels of engulfment have even been correlated with overprotective parenting for patients with T1DM (Raymaekers et al., 2019).

High rejection scores have also been associated with negative health outcomes, particularly poor medication adherence. In patients diagnosed with asthma, patients who rejected their diagnosis were more likely not to follow the medication regimen prescribed for their asthma (Adams et al., 1997). Patients with T1DM who have high rejection scores have similarly been found to have worse adherence to treatment (Oris et al., 2016; Tilden et al., 2005). Along with the effects of higher engulfment scores in patients with congenital heart disease and inflammatory bowel disease already discussed, high rejection scores were also associated with higher levels of emotional distress and greater reporting of physical symptoms in patients with congenital heart disease and with self-reported anxiety and depressive symptoms in patients with irritable bowel disease (Andonian et al., 2020; Knödler et al., 2020; Van Bulck et al., 2018). Additionally, patients with T1DM with high rejection scores were prone to non-disclosure of their diagnoses to others, including healthcare providers (Tilden et al., 2005). As a result of these studies, rejection and engulfment can both be described as maladaptive illness identities.

Acceptance and enrichment, by contrast, can be considered adaptive illness identities as they have been connected to positive health outcomes. In patients with epilepsy, acceptance scores were significantly positively correlated with quality of life

according to the IIQ whereas rejection scores were significantly negatively correlated with quality of life (Luyckx et al., 2018). High acceptance and enrichment scores in patients with inflammatory bowel disease were both correlated with lower levels of depression (Knödler et al., 2020). High acceptance scores in these same patients were also associated with higher self-reported quality of life, lower levels of self-reported childhood trauma, and less significant anxiety and physical symptoms (Knödler et al., 2020). Interestingly, although patients with high levels of acceptance with congenital heart disease also report fewer depressive and anxiety symptoms and lower levels of physical symptoms, patients with high enrichment scores reported more physical symptoms (Van Bulck et al., 2018). In patients with epilepsy, high acceptance scores were correlated with better application of self-control skills (Rosenbaum & Palmon, 1984). High acceptance scores in patients with chronic pain were correlated with lower reports of pain intensity, lower levels of anxiety, depression, physical and psychosocial disability, less avoidance, and better work ability (McCracken, 1998). One study found that an intervention designed around enrichment and cognitive reframing for patients with epilepsy reduced non-productive coping mechanisms (Reeve & Lincoln, 2002).

This wide variety of studies and results concerning illness identity in a variety of patient demographics makes it clear that illness identity is worth studying. As a chronic illness, T1DM has already been the subject of studies on illness identity. However, these studies of illness identity have not gone beyond the conclusions described above. There is limited discussion of exactly why these types of identities are leading to the identified outcomes. This is where incorporating concepts of attribution theory may be helpful by

offering a way to discover what may mediating the effects of illness identity on health outcomes.

# Chapter 3: Attribution Theory

## Attribution Theory in the Setting of Type 1 Diabetes

In this chapter, I will describe attribution theory through the lens of a patient with T1DM. After this discussion, I will summarize the current state of the literature on attribution theory as it has been applied in the medical field.

Attribution theory is based on the idea of causes of outcomes in people's lives and how they perceive those causes. Originally put forward by Fritz Heider (1958), Bernard Weiner (1985) is credited with refining attribution theory to its modern conception. More detailed discussions of the theory can be found in Weiner's many writings and beyond (Weiner, 1985, 1986, 2010), but below I provide a brief explanation of the theory as pictured in Figure 1 through scenarios that an adolescent patient with TIDM might face.

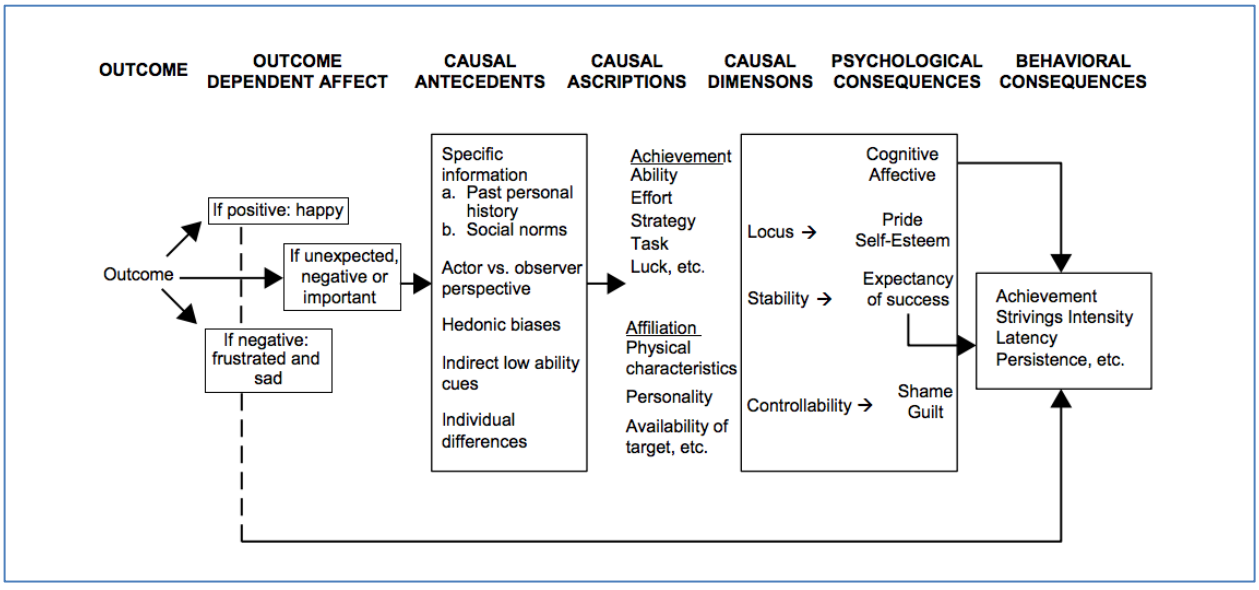


Figure 1. Weiner's Attributional Theory of Intrapersonal Motivation (adapted from Graham & Taylor [2016]).

Let us say that a 15-year old patient with TIDM goes to their pediatric endocrinologist's clinic. As part of their visit, they will have their blood drawn to measure a HbA1c level to determine how their blood sugar has been managed over the past three months. As a result, the "outcome" of their HbA1c level could generate a number of emotions, or "outcome dependent affects," within the patient. If their HbA1c is 6.4%, within the recommended levels of HbA1c < 7.5% for all pediatric patients with T1DM (American Diabetes Association, 2018), the patient would likely consider that a positive outcome. As such, attribution theory would predict that the patient would feel happy because they are maintaining a HbA1c level that should protect them from future negative health consequences. If their HbA1c is 8.2%, that would potentially be a negative outcome. As such, attribution theory would predict that the patient would feel sad and/or frustrated because of the elevated risk for future health problems (Agiostratidou et al., 2017; Andersson et al., 2012; Wang et al., 2019). As an important outcome in the patient's life, the patient will likely do some reflecting on their HbA1c levels, either subconsciously or consciously and either on their own or with the guidance of their healthcare providers and caretakers. This is where attribution theory turns to the idea of causes.

As the patient reflects on their HbA1c levels, they might first consider what attribution theory calls "causal antecedents." Causal antecedents are those facts, characteristics, and phenomena that the individual either consciously or subconsciously identifies as precursors that helped lead to an outcome. This is a broad category that can

include personal traits and history, qualities of the environment or society, and any number of cognitive biases to which all individuals are subject. Antecedents to our patient's HbA1c level in the patient's mind could include such things as the patient's HbA1c levels at their prior appointments, the patient's environment established at home by their caretakers or at school by their teachers and peers, and the patient's access to insulin, syringes, or supplies needed to check their blood glucose, such as a continuous glucose monitor (CGM) that intermittently checks the patient's glucose automatically and provides alerts for high or low blood sugar levels. I next discuss the potential impact of cognitive biases as I move onto causal ascriptions and dimensions.

Each causal antecedent the patient makes is paired with a "causal ascription." Antecedents are ascribed or credited to particular reasons for success or failure, which could be personal traits or something outside of the individual. This ascription process can again be conscious or subconscious. So, when thinking about the outcome of a good HbA1c level of 6.4%, the patient might identify the reminders they have set on their phone to check their blood sugar as an antecedent to the successful outcome. However, they could ascribe that antecedent to a number of other things, like to their inherent organizational abilities or to the effective strategy the alarms represent. Or, when thinking about the outcome of a less desirable HbA1c level of 8.2%, the patient might identify the poor diet they ate over the past month as an antecedent to the negative outcome. And they could ascribe their diet to bad luck that the school cafeteria does not have healthier options or to laziness on the part of their caretakers in preparing meals at home. Altogether, causal antecedents and causal ascriptions can be labelled using three

overarching “causal dimensions”: locus, stability, and controllability, to which I turn next.

Attribution theory identifies three dimensions that describe an individual’s conscious or subconscious causal antecedents and ascriptions for a particular outcome: locus, stability, and controllability. Locus, or *locus of causality*, describes whether an individual believes that antecedents and ascriptions for outcomes come from within themselves as an individual (internal) or from their environment (external). *Stability* describes whether or not a person believes that an antecedent and ascription remain consistent over time (stable) or can change (unstable). Finally, *controllability* describes whether an individual believes that they have influence over the antecedent and ascription (controllable) or that they do not have influence (uncontrollable). Each of these dimensions represents a characteristic that exists on a spectrum.

We can look back at the positive and negative scenarios we have considered to expand upon these concepts. Looking at the antecedents and ascriptions concerning the poor diet if the patient got the less desirable HbA1c of 8.2%, these could be seen by the patient as external, stable, and uncontrollable, as the patient may have no choice or influence over the foods their school or family prepares for them with no hope for change in the future. Alternatively, with the antecedents and ascriptions for the positive outcome of a HbA1c of 6.4%, the patient may see their phone alarms as controllable and unstable, as they can decide to turn them off and on as they desire, but there may be more uncertainty about whether the patient views the alarms as internal or external. The alarms could be considered internal, as the patient is the one that decided to set the alarm, but

they could also be considered external, as their phone is the actual object providing the alarms. Now that I have explained causal antecedents, aspirations, and dimensions, I will quickly return to mention cognitive biases.

It is easy to understand the impact that cognitive biases can have on how individuals view causal antecedents and ascriptions when considering causal dimensions. There are countless cognitive biases that predict how an individual will label causal antecedents and ascriptions with particular causal dimensions. For example, hedonic bias predicts that individuals tend to attribute successes to themselves and failures to something else – in other words, individuals will consciously or subconsciously identify internal, unstable, and controllable causal antecedents as the drivers of their successes and external, stable, and uncontrollable causal antecedents as the drivers of their failures. This means that our 15-year old patient with T1DM with the successful outcome would be predisposed to label their alarms as an internal, unstable, and controllable antecedent because that gives themselves the most credit for successfully implementing that strategy. In the same way, the patient facing a negative outcome would label their poor diet as external, stable, and uncontrollable as this shifts the blame for their struggles to someone else. This is just one of many possible cognitive biases that can influence causal attributions, but further discussions of cognitive biases are beyond the scope of this paper.

According to attribution theory, as an individual considers all of the causal antecedents and aspirations that they believe led to a given outcome, the predominant causal dimensions along with the nature of the outcome as positive or negative lead to

unique psychological consequences. Outcome-dependent affective responses represent an individual's initial feelings towards an outcome, with psychological consequences driven more broadly by the emotions that arise as the individual reflects on the causes of that outcome.

Again, returning to our positive and negative scenarios will allow for an illustration of different possible psychological consequences. Taking the patient who has the admirable HbA1c level of 6.4%, how they will feel and behave following this outcome is dependent on their causal attributions. If the patient believes that the outcome occurred largely due to stable and uncontrollable factors, the patient will likely not be particularly excited, as they feel may feel they had no influence on that outcome because they think their actions had no impact on the positive lab result. If the patient believes the outcome occurred largely due to unstable, controllable, and internal factors, they might feel pride that they were able to manage their T1DM effectively. Finally, if the patient believes that the outcome occurred largely due to unstable and controllable but external factors, they might be grateful that those external factors, such as a supportive family and school system, exist. On the other side of the spectrum, if the patient believes that the less favorable outcome of a HbA1c of 8.6% was due to stable and uncontrollable factors, they might give up hope of ever improving their blood sugar levels at future visits. If the patient believes the outcome occurred largely due to unstable, controllable, and internal factors, they might feel shame that they did not do a better job managing their T1DM. Finally, if the patient believes that the outcome occurred largely due to unstable, controllable, and external factors, they might become frustrated that those external factors

are not in their favor. Finally, these psychological consequences lead to behavioral consequences.

As a theory of motivation, the prediction of behavioral consequences of casual attributions is a primary concern for attribution theory. The confluence outcome dependent affect, causal attributions, and psychological consequences is primarily consequential for researchers because a greater understanding of all of these elements of attribution theory can lead to more accurate predictions of an individual's future behaviors. The prideful patient who achieved the commendable HbA1c level due to perceived internal, unstable, and controllable causes will likely have their health-supporting behaviors reinforced, and are likely to want to continue to maintain successful control of their blood sugars. By contrast, the shamed patient who struggled to control their HbA1c due to perceived internal, unstable, and controllable causes might feel compelled to change their behaviors to take better control of their health, as they believe they have the ability to achieve better outcomes in the future. If the patient attributes their outcome to an external cause, they might thank that external cause such as a parent if the outcome was positive and continue to follow their instructions moving forward or petition their parent to provide better food choices with less sugar if the outcome was negative. Finally, patients who attribute a positive or negative HbA1c outcome to uncontrollable and stable causes will likely not change their behavior to improve their health, because they consider the outcome to be out of their control.

As this example attempts to show, attribution theory can be applied effectively to patients and to illnesses like T1DM. It is worthwhile to study patient's casual attributions

in an attempt to not only predict their health behaviors, but also to develop interventions to change causal attributions in order to promote positive health behaviors. Investigating whether a patient believes that their illness comes from themselves or their environment, that their condition is stable over time or constantly changing, and that they do or do not have control over their illness gives healthcare providers useful indicators of whether patients will take the medications that they are prescribed, go to appointments wo which they are referred, and countless other potential behaviors. If every patient viewed their health as being controlled by unstable, controllable, and internal antecedents, this might lead to the greatest motivation to maintain treatment adherence and develop good habits for their health. So far, Weiner's attribution theory has not been utilized extensively as a whole in medical populations, but bits and pieces of it have been researched extensively, and this is what I review in the next section.

## ATTRIBUTION THEORY LITERATURE

Although attribution theory has been explicitly utilized within the healthcare field, its application has spanned a wide variety of concerns within the healthcare field. Often, the attributions studied have not been the attributions of patients but the attributions that healthcare workers or those of someone within a patient's social network. And, the focus of research regarding patient attributions has sometimes focused on attributions made outside of their illness or treatments. Finally, those studies that did concern attributions patients made regarding their treatments or the origin of their illness have stopped short of investigating how causal attributions impact a patient's health outcomes or behaviors.

A number of studies have examined what attributions are made by those around a patient, including their healthcare providers and social support systems. Attribution theory has been utilized to examine how our ever-growing understanding of genetics has led providers to value genetic factors of physical illnesses too highly and believe conditions are more stable and uncontrollable (Dar-Nimrod & Heine, 2010). Additionally, for this same reason, providers have higher beliefs that mental illnesses are more stable, less controllable, and more likely to be shared within families (Phelan, 2005). Attribution theory has been used to examine why providers believe that treatments work, such as why physical therapy works (Stenmar & Nordholm, 1994). The attributions that healthcare providers make in interactions between one another have also been studied, such as during conversations between physicians and physical therapists (Curtis, 1994). Researchers have examined how nurses treat and view their patients based on whether or not the attributions they have regarding their patient's illness align with the patient's attributions (Allen, 1990). One area of research that has been frequently studied is the attributions that family members of patients make about their relative's illness based on their levels of expressed emotions (Barrowclough & Hooley, 2003). Similarly, the causal attributions of relatives of patients with schizophrenia predicted patient relapse in a Chinese population (Yang et al., 2004). Not surprisingly, the attribution framework has been utilized in medical education settings, such as thinking about a learner's attributions or their ability to identity patient attributions (Smith et al., 1998).

When attribution theory is studied in patient populations, researchers sometimes examine attributions that patients make outside of their illnesses, treatments, or health

behaviors. One group of researchers has looked at patient attributions regarding their physician's response to discussions of patient internet research as well as patient decisions not to discuss that information with physicians, in an investigation of effective communication strategies for physicians (Bylund et al., 2007; Imes et al., 2008; Sabee et al., 2007; Sabee et al., 2012). Similarly, another study examined the attributions patients made regarding a provider's decision to limit or deny opioid medications for pain to optimize discussions of this difficult topic (Matthias et al., 2013). Attribution theory has also been utilized to show that patients, particularly female patients, report greater satisfaction with healthcare services when they attribute the decision to stay in the hospital internally rather than externally (Woodside et al., 1987).

One application of attribution theory close to the goals of my study involved studying the attributions patients made regarding the reasons for the success of their treatments or therapies. German et al. (2014) designed a rating system to examine if patients were attributing the benefits of cognitive behavioral therapy for their depressive symptoms to cognitive, behavioral/environmental, or problem-solving causes. Llewelyn (1988) found that during therapy sessions, clients attributed benefit to reassurance and problem-solving discussions, even though providers attributed benefit to the development of insight through discussions of the origin of their symptoms.

A handful of researchers have explored whether or not patients are able to attribute symptoms to proper diagnoses, attributions patients make about the origins of their illnesses, how patient characteristics can impact attributions patients make regarding their illnesses, and how patient attributions can impact patient education. In primary care

settings in India, patients have been found to avoid attributing any somatic symptoms to mental health disorders, even as providers were able to recognize that depression and anxiety were often the primary cause of their symptoms (Andrew et al., 2012). Patients with polymyalgia rheumatica have been found to have no attributable cause for their illness in up to 55% of patients, whereas those that do identify attributable causes attribute their illness to such factors as age, medications, and stress (Tshimologo et al., 2016). Breast cancer patients in Brazil were found to attribute their diagnosis to psychological causes (Pueker et al., 2016). Similar studies have been performed regarding patients with other forms of cancer, chronic fatigue, mental illness, and more (Cho et al., 2008; Ikwuku et al., 2014; Kestemont et al., 2016; Peuker et al., 2015). In patients with panic disorder, characteristics such as age, biological sex, duration of time with their diagnosis, family history of psychiatric illnesses, and previous psychotherapy were able to predict patient viewpoints about the origin of their panic disorder (El Amiri et al., 2018). Patient attributions regarding locus of control have been found to impact the effectiveness of health education materials (Holt et al., 2000).

Finally, some research has been done to examine how a patient's attributions affect their symptoms and their health behaviors. When attribution theory has been applied to patients (Sensky, 1997), it often focuses on psychological or behavioral outcomes. In one meta-analysis of 27 studies in a variety of patient populations, patients who held more internal, unstable, and controllable attributions regarding their illness were associated with positive coping mechanisms which led to better psychological adjustment to diagnoses (Roesch & Weiner, 2001). At the same time, uncontrollable

attributions were associated with negative coping mechanisms which led to worse psychological adjustment to diagnoses (Roesch & Weiner, 2001). However, the findings about patient attributions have not always been consistent, even within the same condition. In patients with end-stage renal disease, the association between a patient's belief about their illness's controllability and their depressive symptoms depended on whether or not the patient had previously experienced a failed renal transplant: high belief in illness controllability was associated with lower depressive symptoms in patients who had not experienced a failed renal transplant but with higher depressive symptoms in patients who had (Holman & Gregory, 1991).

Attributions patients make regarding their illnesses have been used to analyze physical symptoms and health related behaviors as well. In cancer patients, those patients with an external locus of control were found to rate their pain as less severe (Nebemkis et al., 1981). And, although cancer survivors identified many possible causes for their diagnosis, only patients who reported contemplations of external locus of control, such as asking themselves "why me," reported more cancer-related problems (Ferrucci et al., 2011). One group of researchers in the UK used attribution theory to assess whether or not patient attributions led to behavior change. In 155 patients who experienced their first myocardial infarction, French et al. (2005) found no correlations between causal attributions regarding their myocardial infarction and later behavior change. However, another study found that behavior attributions in patients who experience cardiac events were beneficial to the patient's short-term control appraisals and influenced those patients in the form of increased symptoms of anxiety two years following their diagnosis

(Bennett et al., 2016). Women with urinary incontinence were found to be more likely to forgo formal treatment and find ways to self-treat if they attribute their incontinence to aging (Locher et al., 2002).

One specific population whose causal attributions have been research is patients with end-stage renal disease. These patients undergo frequent peritoneal dialysis or hemodialysis treatments, typically three times per week for multiple hours at each session for hemodialysis, and are often prescribed  additional complicated therapies, including multiple medications and restrictions on their diet and fluid intake. Researchers have been investigating a number of different patient traits to try to understand what determines a patient's quality of life as well as whether or not a patient will be able to comply with their treatments (Pucheu et al., 2004). Patients with high perceived control and preference for control of their end-stage renal disease have been found to exhibit the most effective adherence to their treatment (Howren et al., 2016). One study in patients with end stage renal disease found that patient attributions about past attempts at compliance were associated with current compliance with their prescribed fluid restriction (Friend et al., 1997). Health locus of control has been found to affect adherence to diet and fluid restrictions as well (Sensky et al., 1996).

A likely cause for the seemingly small number of studies regarding causal attributions and health-related outcomes and behaviors is the existence of another line of research that discusses essentially the same idea, particularly with regards to patients' beliefs regarding the controllability of their illness. That is the concept of illness

representation that has been widely adopted in health psychology research, and I will turn to that concept now.

# Chapter 4: Illness Representations and Controllability

## The Common-Sense Model of Self-Regulation

In this chapter, I turn to illness representations and the concept of controllability as it is described by Leventhal et al. (1998) in the Common-Sense Model (CSM) of Self-Regulation. After this discussion, I summarize the current state of the literature on controllability of illness from the viewpoint of the CSM.

Although attribution theory has not gained significant traction on its own within medicine, causal attributions can be found within the important concept of illness representations and how it influences patient self-regulation. The specific theory most cited with these discussions is the perceptual-cognitive model of self-regulation, often shortened to the CSM (Leventhal, 1998). The history of the model and the work of Howard Leventhal and his many colleagues will help lay a foundation to explicate the model thoroughly.

Howard Leventhal (1950) began by hoping to understand how people make important decisions about their health, specifically what inspires individuals to self-regulate their health behaviors. He began by investigating messaging and responses to health concerns, specifically those around tetanus and the risk of lung cancer with cigarette smoking. He was seeking to evaluate the Fear-Drive model of behavior as formulated by John Dollard and Neal Miller (1950). This model claimed that fear acts as a motivational state, reinforcing actions that minimize fear (Dollard & Miller, 1950). To investigate this claim, Leventhal designed two studies concerning tetanus and one study concerning smoking that involved investigating the effect that high-fear messages

(graphic, personal language with color pictures) had on attitudes and behaviors compared to low-fear messages (technical, impersonal language with black-and-white pictures) (Leventhal et al., 1966; Leventhal et al., 1965; Leventhal et al., 1967). Whereas high-fear messages did change attitudes more effectively in the few days following the reception of those messages, the change did not last long, and, more importantly in Leventhal's mind, there was no difference in subsequent behaviors unless the messaging was combined with a specific action plan for the study participants to follow (Leventhal & Niles, 1965). These studies helped to reveal the shortcomings of the Fear-Drive model, including the fact that the actions plans when presented alone were also ineffective in changing behaviors. These results inspired Leventhal (1970) to create the parallel process model.

The parallel process model became the starting point for Leventhal et al.'s (1980) CSM. This model posited that the fear an individual feels regarding a health threat requires the individual to form a perception of the danger to health, with the threat leading to actions that an individual will use to cope with or control the danger and their fear (Leventhal, 1970). This leads to a self-regulatory cycle of processing information about an illness, developing a plan to cope with and reduce fear and danger, assessing the efficacy of those actions, and repeating (Leventhal et al., 2002). Leventhal found that the key to promoting legitimate actions was this interplay between the stimuli an individual experiences and the representation of what that means to that individual.

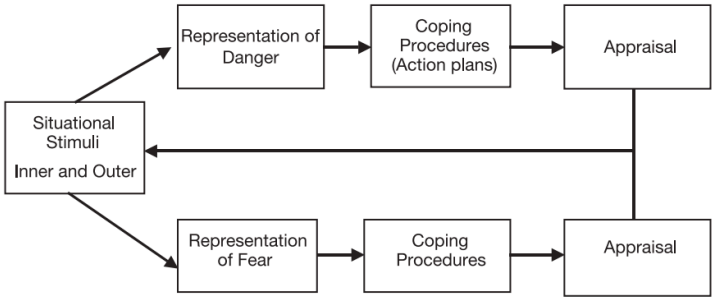


Figure 2. The Parallel Process Model (Leventhal et al., 2002).

Without the combination of symptoms and patients perceiving or labeling those symptoms as part of a health threat, Leventhal and his colleagues found that changes in behavior would not occur. The first demonstration of this came from a study of women and their levels of worry about receiving cancer diagnoses (Easterling & Leventhal, 1989). Women who both experienced symptoms and believed their chances for cancer were high exhibited the most worry. Women who only experienced symptoms or only believed that their chances of being diagnosed with cancer were high without symptoms experienced significantly less worry. Leventhal and his colleagues found that this combination led to impacts beyond an individual's psychological feelings and behaviors, so that worry led to concrete health behaviors such as taking blood pressure medications as prescribed (Meyer et al., 1985). The only problem left with the model became its simplicity. Although symptoms are often a large part of an individual's perception of what makes up an illness, common sense told Leventhal and his colleagues that there

would be more to how an individual conceives of illnesses, and their research found that to be true.

Through additional studies, Leventhal and his colleagues expanded the parallel process model to include an idea of illness representations that involve five different elements. The name CSM comes from the idea that a patient's illness representation refers to a patient's common-sense understanding of a health threat (Leventhal et al., 2002). Through a number of qualitative studies involving interviews of patients with various illnesses and with quantitative analysis regarding beliefs about illnesses, Leventhal and his colleagues (2002) eventually settled on five aspects that encapsulate an individual's illness representation: identity[1], timeline, causes, consequences, and control (Leventhal et al., 2002). An illness's identity includes the symptoms or labels used to describe the illness, so this parallels the idea that Leventhal and his colleagues had initially conceived of with the parallel process model. The timeline and causes are relatively straightforward, representing the time course of an illness and how an illness originates, respectively. The consequences of an illness include both the real and imagined ramifications of an illness in the patient's mind. Finally, control concerns a patient's belief regarding their ability to prevent, maintain, or cure an illness. This significant expansion of how Leventhal and his colleagues approached and examined a

[1] Note that "identity" as it is used here is distinct from discussions of "identity" and "illness identity" previously. This form of "identity" concerns the identity of the illness as defined by its name and symptoms. This is not significant moving forward, but providing a differentiation to avoid confusion felt necessary.

patient's illness representation was incorporated into their original parallel process model to create the CSM.

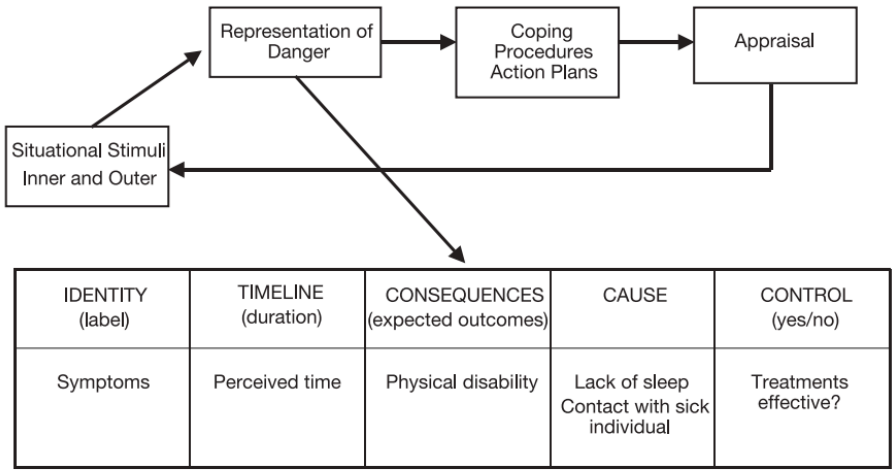


Figure 3. The Common-Sense Model of Self-Regulation (Leventhal et al., 2002).

With all of the work that Leventhal and his colleagues did to establish the CSM, other researchers decided to take this framework and adapt it into a questionnaire format to effectively provide quantitative data regarding patients and their illness representations. John Weinman and Rona Moss-Morris (1996) are two of the key researchers who initially created the Illness Perception Questionnaire (IPQ). This 26-item questionnaire, using a five-point scale from strongly disagree to strongly agree, investigated and provided a number score to evaluate a patient's perceived identity/symptoms, cause, timeline, consequences, and control of their illness. After examining this questionnaire in a number of different patient populations, the researchers eventually modified the questionnaire to create the 38-item Revised Illness Perception

Questionnaire (IPQ-R) that incorporated questions regarding a patient's emotions in relation to their illness and provided subscores to distinguish whether patients felt their treatments provided control over their illness or whether they felt they personally had control (Moss-Morris et al., 2002). Since their creation, thesetwo questionnaires have been utilized in numerous studies to support Leventhal's CSM and to provide a greater understanding of how patients illness representations can help predict health behaviors.

The extensive work Leventhal and others have done to support the CSM and create the IPQ-R provide an invaluable resource to any endeavor to connect illness identity and causal attributions because of the parallels that exist between attribution theory and the CSM. As the reader might notice, cause and control within this theory mirror locus of causality and controllability within attribution theory, respectively. As a result, although perceived controllability of illnesses may not have been studied within the framework of causal attribution theory up to this point, perceived control within the CSM has received attention. Below, I will discuss the current literature on perceived control as it has been presented.

## Illness Representation and Controllability Literature

The IPQ and IPQ-R have been used extensively to study a wide variety of patient populations. Although significant findings have been found in relation to all five categories of illness representation according to the CSM, controllability became particularly interesting as a significant and actionable element of illness representation upon which to focus. Because of the wide possibilities of causes between different

illnesses and the relatively complex etiology of T1DM, I decided to focus on controllability over causality – both whether the patient believes they personally have control over their illness (personal controllability) and whether they believe their treatment will provide control over their illness (treatment controllability) (Moss-Morris et al., 2002). Researchers have found significant findings regarding positive health behaviors and symptomatology with controllability using both the IPQ and IPQ-R in a wide variety of illnesses and populations.

With the original IPQ, high perceptions of controllability were associated with health benefits for patients, and lower perceptions of controllability were associated with negative health outcomes. In patients with rheumatoid arthritis, chronic obstructive pulmonary disease, and psoriasis, high controllability scores were associated with higher levels of functionality (Scharloo et al., 1998). In patients with HIV, low perceived controllability scores were associated with fewer and less effective self-care activities as well as lower health functioning according to quality-of-life measures (Reynolds et al., 2009).

Similar results were reported with the IPQ-R. In patients with heart failure, high control scores in general were positively correlated with self-reported general health (Lerdal et al., 2019), and those with high treatment control scores specifically were positively associated with increased self-care practices (MacInnes, 2003) and decreased symptoms of anxiety and depression (Nahlen Bose et al., 2016). In patients with hip or knee arthroplasties, high personal control scores were positively associated with fewer hours in pain per day (Lindberg et al., 2016), and high treatment control scores were

positively associated with measures of self-efficacy (Magklara & Morrison, 2016) and negatively associated with measures of depression and anxiety (Pinto et al., 2013; Pinto et al., 2017). In patients with myocardial infarctions, high personal and treatment control scores were negatively associated with measures of physical fatigue, activity, and motivation (Alsen et al., 2010) as well as measures of depression (Dickens et al., 2008). Finally, in patients who underwent coronary artery bypass grafts, high personal control scores were negatively associated with measures of depression, and high treatment control scores were positively associated with high measures of physical quality of life (Stafford et al., 2009). Patients with intestinal failure who required parenteral nutrition at home and who reported low personal control scores had significantly higher levels of emotional distress (Fortune et al., 2005). Patients with asthma with high personal control scores demonstrated greater control of their asthma (Achstetter et al., 2019). In both patients with T1DM and type 2 diabetes, high levels of perceived personal control led to greater blood glucose control (Broadbent et al., 2011).

Although these results provide great credence to the fact that controllability as measured by the IPQ-R contributes valuable information to predict health behaviors in a wide variety of adult populations, there are fewer studies in pediatric and adolescent populations. Thankfully, they demonstrate similar results. In adolescent patients with hypertension, high perceived treatment control scores predicted greater adherence to medications and stress reduction (Zugelj et al., 2010). Adolescent patients with cystic fibrosis who demonstrated low treatment control scores showed higher levels of non-adherence to prescribed antibiotics (Bucks et al., 2009). Finally, perceived control scores

were not associated with higher quality of life in children with cancer, although other aspects of illness representations like consequences, identity, and timeline were (Fonseca et al., 2010).

With everything I have discussed so far, I am ready to propose mystudy. The literature around illness identity and illness representations have demonstrated significant findings in a wide variety of settings, and I believe they need to be considered together. As a result, I predict that investigating illness identity and perceived control in adolescent patients with type 1 diabetes will provide significant outcomes in terms of health behaviors and outcomes, and perceived control will mediate the effects of illness identity.

# Chapter 5: Proposal to Investigate a Possible Mediation Model

In this report, I am designing a study to address the following three research questions:

1. Does the strength of the illness identity of an adolescent patient with T1DM (namely high acceptance and enrichment and low engulfment and rejection measures) and/or causal attributions (namely high controllability measures) predict positive health outcomes?
2. Is there a relationship between the illness identity of pediatric patients with T1DM and their perceived controllability of their illness?
3. Are the effects of the illness identity of a pediatric patient with T1DM on health outcomes mediated by the perceived controllability of their illness? In other words, do the associations between illness identity measures and health outcomes for pediatric patients with T1DM hold when controlling for perceived controllability of their illness?

## METHODS

### Participants

As Erikson's (1968) widely influential developmental theory postulates, individuals undergoe a stage of identity formation or confusion during the ages of 12-19 years old. Additionally, the American Diabetes Association identifies that early and late adolescence represent important time periods in terms of patients developing more

decision-making capabilities and autonomy regarding their T1DM care (Chiang et al., 2018). As a result, the proposed study will target 100 patients at pediatric endocrinology clinics in Texas diagnosed with T1DM between the ages of 12 and 18 (to remain within pediatric populations). And because the first 12 months after a diagnosis with T1DM comes with such high levels of change and unpredictability (Pihoker et al., 2018), individuals who have been diagnosed with T1DM within the last year will be excluded.

## Measures

### *Illness Identity Scores*

In order to measure the four sub-categories of illness identity, I will utilize the IIQ, a tool perfectly suited to this study as it was developed specifically to study illness identity with patients with T1DM (Oris, et al., 2016). This 27-item questionnaire measures a patient's engulfment, rejection, acceptance, and enrichment as relates to their diagnosis of T1DM (e.g., "my diabetes completely consumes me," "I just avoid thinking about my diabetes," "I am able to place my diabetes in my life," and "Because of my diabetes, I have become a stronger person") using a five-point scale (1 = strongly disagree and 5 = strongly agree). The scores for each question are added together to provide an overall score for each category of illness identity. The subscales for each aspect of illness identity have exhibited good internal reliability: engulfment ($\alpha \geq .90$), acceptance ($\alpha \geq .85$), rejection ($\alpha \geq .84$), and enrichment ($\alpha \geq .90$). See the full IIQ in Appendix A.

### *Causal Attribution Scores*

The causal attribution of illness controllability has been studied through the personal control and treatment control subscales of the Revised Illness Perception Questionnaire (IPQ-R), designed with Leventhal's CSM of illness representation in mind (Moss-Morris, et al., 2002) These two subscales include 11 items in total (e.g., "There is a lot which I can do to control my symptoms" and "the negative effects of my illness can be prevented (avoided) by my treatment") also using a five-point scale (1 = strongly disagree and 5 = strongly agree). The scores for each question within the personal controllability and treatment controllability category added together provide the overall score for personal and treatment controllability, respectively. High scores indicate that a patient feels they have more control over their illness, either personally, through their treatments, or both if both scores are high. Since its development, the IPQ-R has been validated in multiple patient populations including myocardial infarction (Brink, Alsen, & Cliffordson, 2011), weight loss surgery (Surgenor et al., 2019), and musculoskeletal disorders (Leysen et al., 2015), and in multiple languages other than English including Malay (Chew et al., 2017), Swedish (Brink, Alsen, & Cliffordson, 2011) and Chinese (Wu et al., 2018). Both subscales have exhibited good internal consistency reliability: personal control ($\alpha \geq .81$) and treatment control ($\alpha \geq .80$). See the full IPQ-R subscales used in this study in Appendix B.

### *Health Outcomes*

HbA1c, or glycated hemoglobin, is a form of hemoglobin that has a sugar molecule bound to it. HbA1c informs a provider how well a patient has been managing

their blood sugars by providing a proxy measure of the average amount of glucose in the blood over the course of three months. As mentioned previously, a HbA1c < 7.5% is recommended for all pediatric patients according to American Diabetes Association guidelines (American Diabetes Association, 2018), and elevated HbA1c levels are associated with many risks, adverse outcomes, and all-cause mortality in type 1 and type 2 diabetes (Agiostratidou et al., 2017; Andersson et al., 2012; Wang et al., 2019).

The Problem Areas in Diabetes (PAID) provides a measure of the emotional state and mental health of patients with diabetes (Welch, Jacobson, & Polonsky, 1997). The 20-item scale provides a global score of diabetes related emotional distress (e.g., "feeling alone with diabetes") through a five-point scale (0 = not at all and 4 = serious problem). The scores for each question are then added together and multiplied by 1.25 to give a standardized score out of 100, with scores over 40 indicating higher levels of patient distress with regards to their T1DM. PAID has exhibited good internal reliability ($\alpha \geq .95$). See the full PAID in the Appendix C.

**Procedure**

Participants will be recruited at routine appointments with their pediatric endocrinologist. After receiving consent from the parents and patients for study participation, patients will provide demographic information (age, race, gender, and date of diagnosis) and fill out the IIQ, IPQ-R, and PAID as part of their routine check-in. Then, as part of their appointment, the patient's blood will be drawn in order to obtain

their HbA1c results. All of this will take place in the waiting room and patient rooms at the endocrinology office.

After collecting these data, I will run correlations between every possible pair of the collected variables controlling for all other variables – age, gender, race, age since diagnosis, HbA1c levels, PAID survey results, engulfment, enrichment, rejection, and acceptance scores, and patient control and treatment control scores. After running these preliminary correlations, I will use hierarchical multiple regression to test the indirect effects of the variables on the health outcomes, paying particular attention to whether or not controllability scores mediate the effects of identity measures on the measured health outcomes.

## EXPECTED RESULTS

### Research Question 1:

Does the strength of an individual's illness identity (namely high acceptance and enrichment and low engulfment and rejection measures) and/or causal attributions (namely high controllability measures) predict positive health outcomes?

In accordance with prior studies of illness identity, including in patients with T1DM, I expect a significant positive correlation between acceptance and enrichment scores and the positive health outcomes of a well-controlled HbA1c (< 7.5%) and a lower score on the PAID scale (See Figure 4). And I expect a significant correlation between rejection and engulfment scores and the negative health outcomes of a poorly controlled HbA1c and a higher score on the PAID scale. Additionally, I expect a significant

correlation between perceived controllability scores and better health outcomes, namely well-controlled HbA1c levels and lower scores on the PAID scale. See Figure 2 for a representation of these expected results.

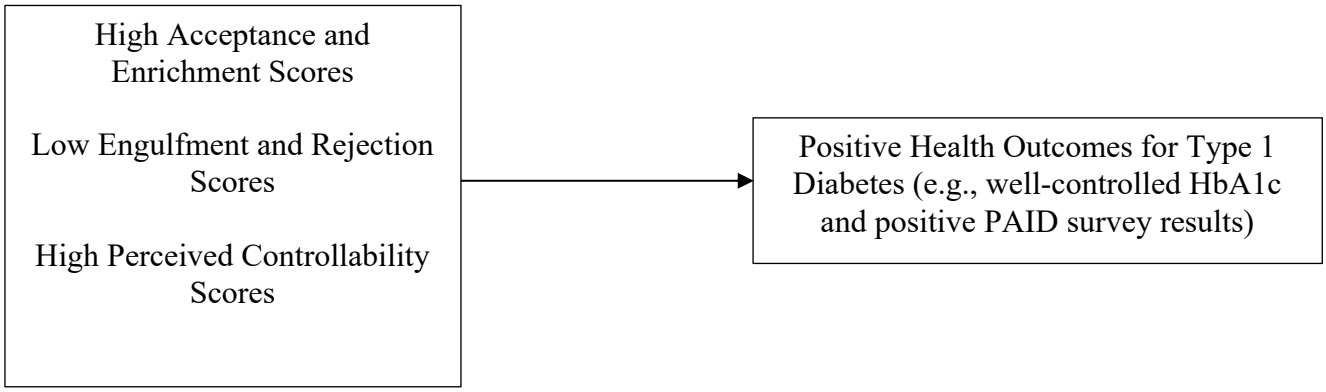


Figure 4. Relationship between Illness Identity, Perceived Controllability, and Health Outcomes.

**Research Question 2:**

Is there a relationship between illness identity and perceived controllability?

For patients with T1DM, I expect that there will be a significant positive correlation between patients' acceptance and enrichment scores and their perceived controllability scores. In addition, I expect that there will be a significant negative correlation between patients' engulfment and rejection scores and their perceived controllability scores.

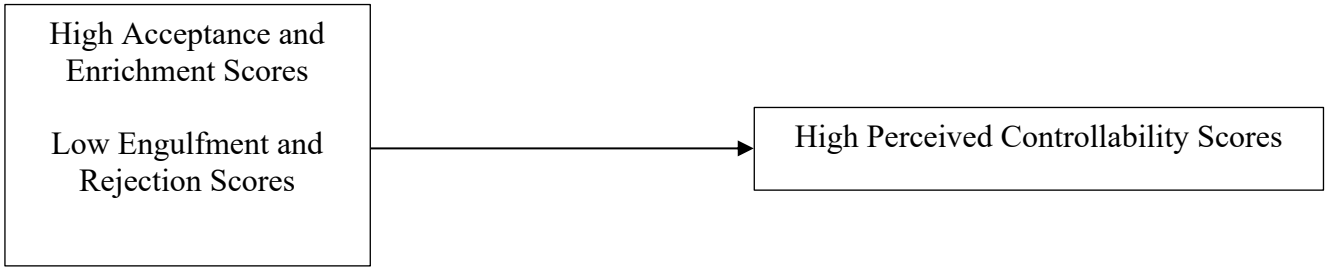


Figure 5. Relationship between Illness Identity and Perceived Controllability.

**Research Question 3:**

Are the effects of a patient's illness identity on health outcomes mediated by controllability of the illness or vice versa? In other words, do the associations between illness identity measures and health outcomes hold when controlling for controllability of the illness or vice versa?

I expect that patients' perceived controllability concerning their T1DM will mediate the relationship between their identity subscores and their health outcomes as measured by their HbA1c's and PAID scores (See Figure 6). In other words, I believe that patients who accept their diagnosis of T1DM and see it as enriching their lives are more likely to perceive T1DM as controllable. This in turn will lead to the better health outcomes initially associated with the acceptance and enrichment scores. By contrast, patients who reject and feel engulfed by their diagnosis of T1DM are more likely to perceive their illness as uncontrollable. This will lead to the negative health outcomes

initially associated with the rejection and engulfment scores. I expect this to be true even controlling for variables such as patient age, gender, race, and time since initial diagnosis.

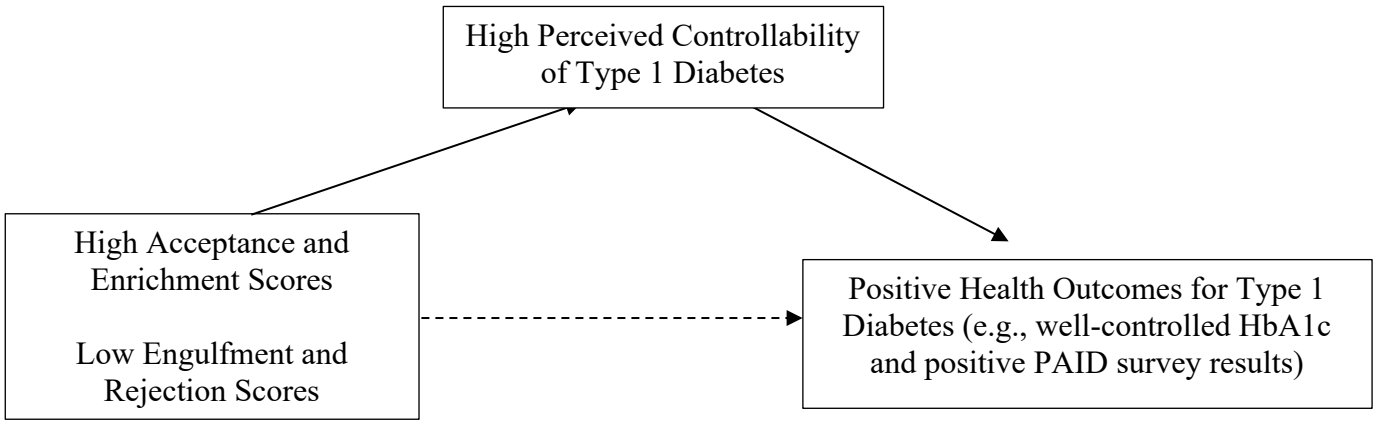


Figure 6. Proposed Mediation Model.

# Chapter 6: Conclusion

## IMPLICATIONS

The proposed research would provide a significant benefit to the literature concerning the connections among illness identity, causal attributions, and health outcomes. First, this study would provide a connection between illness identity and a health outcome beyond simply a behavior or a mental health outcome by using HbA1c measures for patients with T1DM. The strong impact illness identity has on mental health outcomes has already been studied to a significant degree, but the current study would perhaps prompt researchers in the future to examine how illness identity can affect both psychological and physiological health outcomes and beyond.

As an early observational study, the proposed research has the potential to begin expanding upon the relationship between patient identity and health outcomes. Although prior research has revealed significant relationships between various illness identity measures and a variety of patient-related outcomes, this study provides a possible initial step to discovering why illness identity and its different components have the impact on health outcomes that they do.

Finally, as researchers considering these topics have been requesting (Petrie, Jago, & Devcich, 2007), researchers and healthcare providers can begin to use this newly strengthened understanding of how illness identity impacts health outcomes in order to develop interventions that address their patients' perceived controllability to impact health outcomes.

## LIMITATIONS

The proposed study has a number of limitations. As an initial, observational study, the study will feature a relatively small number of patients at a single point in time regarding largely self-reported measures. As a result, concerns surrounding the small sample size or patient biases regarding the self-reported data points could call into question the results found in the study. Additionally, the small sample size obtained from entirely pediatric patients exclusively in Texas may limit the generalizability of the results when thinking about adults or about patients outside of the state of Texas. As the demographics of the patients in the proposed study will likely reflect the demographics of the state, this may potentially leave gaps in patient populations that are not as prevalent in Texas.

## FUTURE DIRECTIONS

A number of future directions exist following a study like this. First and foremost, as I discussed in my introduction, the effect that identity has on medical conditions vary wildly based on the characteristics of those illnesses (Adams et al., 1997; Cruwys & Gunaseelan, 2016; Luyckx et al., 2018; Oris et al., 2016; Reeve & Lincoln, 2002; Rich, 2006; Tilden et al., 2005; Van Bulck et al., 2018). So, although this mediation model may be promising for pediatric patients who have had a chronic medical condition like T1DM for a period of time, it might look completely different for patients diagnosed with T1DM within a year's time, or in other chronic conditions (like asthma), in conditions that are either acute (like fractures) or share characteristics of acute and chronic conditions (like cancer), or in conditions that concern mental health (like depression). Additionally, this

mediation model would need to be investigated in adult populations. Researchers should work to investigate whether this model is accurate with regards to illness identity and controllability in these other patient populations and more.

Second, researchers should expand the scope of the proposed research, and they could do so in a number of ways. The timeframe could be expanded, examining patient illness identity and perceptions of controllability longitudinally in order to examine these relationships over time. Additionally, the sample size could be increased along with the diversity of the patient population in terms of age, race, and where the patients live. This expansion of scope would help ensure the proposed model is generalizable beyond the proposed research.

Potentially most importantly, researchers should work to develop interventions to increase the perceived controllability of patients with T1DM in order to take advantage of the proposed mediation model and maximize positive health outcomes. A number of different avenues have already been pursued for psychosocial interventions in pediatric and adolescent patients with T1DM, but the focus of these have not been on illness identity or perceived controllability. Here I will provide a brief discussion of existing research on these interventions and describe a possible intervention based on existing interventions from educational psychology literature that do concern identity and causal attributions.

There have been three major reviews of psychosocial interventions directed at pediatric and adolescent patients with T1DM (McBroom & Enriquez, 2009; O'Hara et al., 2016; Savage et al., 2010). One review examined 14 randomized controlled trials

concerning the efficacy of seven patient education, five psychosocial, and two family therapy interventions in pediatric patients with T1DM and concluded that although all of the interventions lead to some positive outcome, the psychosocial and family therapy interventions, particularly those grounded in some theoretical framework and developed from relevant literature, demonstrated more significant health outcomes, including significant improvements in patients' HgA1c (Savage et al., 2010). However, none of the studies were grounded in illness identity or causal attribution frameworks (Savage et al., 2010). Another review focused specifically on nine family-centered therapy interventions with similar timeframes and patient age ranges obtained similar findings (McBroom & Enriquez, 2009). The interventions improved patient HgA1c levels, enhanced family dynamics, and decreased family conflict, but again none of the studies investigated illness identity or causal attributions (McBroom & Enriquez, 2009). Finally, a review of interventions for young adults (ages 15-30) with T1DM included six group education or peer-based interventions for patients with type 1 diabetes (O'Hara et al., 2016). The benefits of these interventions were fairly modest, a number of issues were present in many of the studies including small sample sizes, no or un-matched control groups, and the use of unvalidated questionnaires, and again, none of the interventions focused on issues of illness identity or causal attributions (O'Hara et al., 2016). To find interventions on these topics, one must turn to the educational psychology literature.

Although they identified possible concerns regarding the generalizability of the studies, Yeager and Walton (2011) provided a review of psychosocial educational interventions regarding concerns of identity and attributions, and they found powerful

results with certain contexts and individuals. Some of the recurring themes from studies in their review included the presence of the power of peers in an intervention as well as an individual writing exercise. For example, within the context of stereotype threat, low- and middle-income black 7th grade students and women in college physics classes experienced significant increases in GPA at the end of their semester (in addition to two years later for the black students) when those students wrote for 15 to 20 minutes about personal values that were important to them at the beginning of class at the start of their semesters (Cohen et al., 2006; Cohen et al., 2009; Miyake et al., 2010). Having the participants in the intervention play an active role in writing words consistent with their positive identities was crucial for the impact of the intervention as a whole. Additionally, peer involvement facilitated the ability of the participants to retrain their own attributions because of their shared identities with the older peers. For example, Wilson and Linville (1982, 1985) showed that having freshmen in college watch videos where upperclassmen describe initial academic struggles with eventual improvement in grades over time caused a statistically significant increase in GPA as the students learned to attribute setbacks to unstable factors.

Two small studies within adolescent populations with T1DM have shown promise for the peer intervention structure and for focusing on identity. One prospective pilot intervention from the O'Hara et al. (2016) review involving three peer support groups of six to seven college-aged students each meeting weekly for 90 minutes with a 30 minutes formal presentation followed by 60 minutes of open group discussion revealed a statistically significant ($p < 0.001$) improvement in HbA1c levels after 10 weeks

(Shalom, 1991). Additionally, one more recent study from the same Belgian researchers interested in illness identity investigated the association of benefit finding in adolescent patients with T1DM with identity exploration (Luyckx et al., 2016). This idea of benefit finding matches what is meant by an enrichment illness identity as the patients were encouraged to find the benefits that exist with having a diagnosis of T1DM. Because adolescents with T1DM have been found to engage in less identity exploration compared to their healthy peers (Luycx et al., 2008), the researchers decided to investigate and found that adolescents with T1DM with higher scores on measures of benefit finding exhibited greater degrees of identity exploration over a three-year period (Luyckx et al., 2016). The importance of peers and writing in identity-based interventions in educational psychology, the findings from these two smaller studies, and Oyserman's identity-based motivation theory inspired an initial intervention targeting the illness identity and perceived controllability of T1DM in pediatric and adolescent patients.

A compelling framework for how identity can have a huge impact on an individual's motivation and actions is Oyserman's identity-based motivation theory (Oyserman et al., 2017). This theory contains three key features: dynamic construction of identity, interpretation of experience, and action readiness. The fact that identity is dynamically constructed means that different elements of an individual's identity can take different forms and be more or less influential in an individual's motivations and actions in different contexts. For example, while playing in a basketball game, a patient with T1DM likely identifies as a basketball player before identifying as an individual with T1DM, which may impact the likelihood that the individual will stop in the middle

of the game to check their blood sugar even if it would be incredibly likely for the patient to do so at home. Interpretation of ease investigates how an individual's identity can lead to different interpretations of perceived ease or difficulty. Individuals may be motivated to act when they interpret a situation as easy as it could suggest possibility or when they interpret a situation as difficult as it could suggest importance. Or, they might be demotivated in either case as ease may suggest a lack of importance whereas difficulty may suggest impossibility. For example, a patient recently diagnosed with T1DM might interpret that the difficulties they are experiencing monitoring their blood glucose levels and administering shots of insulin mean that it is impossible to control their blood sugar, and that might lead to a rejection of their identity as a type 1 diabetic. Finally, action readiness refers to the fact that people prefer acting in ways that they believe fit their relevant identity. Returning to the basketball example, the individual may be choosing to neglect to check their blood sugar because doing so would make them a bad basketball player in their mind, and it may have nothing to do with their identity as a patient with T1DM.

With this theory in mind, a one-time intervention focusing on illness identity and perceived controllability for patients aged 12-19 with T1DM may be possible. The intervention could involve eight videos of stories from older adolescents and young adults with T1DM discussing how their illness identity shifted from a maladaptive identity of engulfment or rejection to an adaptive identity of acceptance or enrichment (two stories for each transition), similar to discussions of academic difficulty in an educational psychology identity-based intervention (Wilson & Linville, 1982, 1985). In

these stories, the adolescents and young adults could emphasize differences in their attributions about the controllability of their T1DM, differences in their perceptions regarding the difficulty of managing their T1DM, and differences in how their identity as a patient with T1DM interacts with their other identities. After watching these eight videos, the patient would then write for 15 to 20 minutes about how T1DM has positively impacted their lives, an activity reminiscent of the educational identity-based motivation interventions and the benefit finding study (Cohen et al., 2006; Cohen et al., 2009; Luyckx et al., 2016; Miyake et al., 2010).

Interventions like the one described above could capitalize on the proposed mediation model in Figure 6. If healthcare providers can find effective ways of increasing their patients' perceived controllability of their illnesses, patients will become more motivated to pursue positive health behaviors leading to significantly improved health outcomes.

# Appendices

## APPENDIX A: ILLNESS IDENTITY QUESTIONNAIRE (IIQ)

1. I refuse to see my diabetes as part of myself.
2. I'd rather not think of my diabetes.
3. I never talk to others about my diabetes.
4. I hate being talked to about my diabetes.
5. I just avoid thinking about my diabetes.
6. My diabetes simply belongs to me as a person.
7. My diabetes is part of who I am.
8. I accept being a person with diabetes.
9. I am able to place diabetes in my life.
10. I have a clear picture or understanding of my diabetes.
11. I have learned to accept the limitations imposed by my diabetes.
12. My diabetes dominates my life.
13. My diabetes has a strong impact on how I see myself.
14. I am preoccupied with my diabetes
15. My diabetes influences all my thoughts and feelings.
16. My diabetes completely consumes me.
17. It seems as if everything I do is influenced by my diabetes.
18. My diabetes prevents me from doing what I would really like to do.
19. My diabetes limits me in many things that are important to me.
20. Because of my diabetes, I have grown as a person.
21. Because of my diabetes, I know what I want out of life.
22. Because of my diabetes, I have become a stronger person.
23. Because of my diabetes, I realize what is really important in life.
24. Because of my diabetes, I have learned a lot about myself.
25. My diabetes has brought me closer to my friends and family.
26. Because of my diabetes, I have learned to work through problems and not just give up.
27. Because of my diabetes, I have learned to enjoy the moment more.

Note:
Questions 1 - 5 – Rejection items
Questions 6 - 11 – Acceptance items
Questions 12 - 19 – Engulfment items
Questions 20 – 27 – Enrichment items

## APPENDIX B: REVISED ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

1. There is a lot which I can do to control my symptoms.
2. What I do can determine whether my illness gets better or worse.
3. The course of my illness depends on me.
4. Nothing I do will affect my illness. (r)
5. I have the power to influence my illness.
6. My actions will have no effect on the outcome of my illness. (r)
7. There is very little that can be done to improve my illness. (r)
8. My treatment will be effective in curing my illness.
9. The negative effects of my illness can be prevented (avoided) by my treatment.
10. My treatment can control my illness.
11. There is nothing which can help my condition. (r)

Note:
Questions 1 - 6 – Personal Control items
Questions 7 - 11 – Treatment Control items
(r) = items are reversed scored

## APPENDIX C: PROBLEM AREAS IN DIABETES (PAID)

1. Worrying about the future and the possibility of serious complications.
2. Feeling guilty or anxious when you get off track with your diabetes management.
3. Feeling scared when you think about living with diabetes.
4. Feeling discouraged with your diabetes regimen.
5. Worrying about low blood sugar reactions.
6. Feeling constantly burned-out by the constant effort to manage diabetes.
7. Not knowing if the mood or feelings you are experiencing are related to your blood glucose.
8. Coping with complications of diabetes.
9. Feeling that diabetes is taking up too much mental and physical energy.
10. Feeling constantly concerned about food.
11. Feeling depressed when you think about living with diabetes.
12. Feeling angry when you think about living with diabetes.
13. Feeling overwhelmed by your diabetes regimen.
14. Feeling alone with diabetes.
15. Feelings of deprivation regarding food and meals.
16. Not having clear and concrete goals for your diabetes care.
17. Uncomfortable interactions around diabetes with friends or family.
18. Not accepting diabetes.
19. Feeling that friends or family are not supportive of diabetes management efforts.
20. Feeling unsatisfied with your diabetes physician.

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